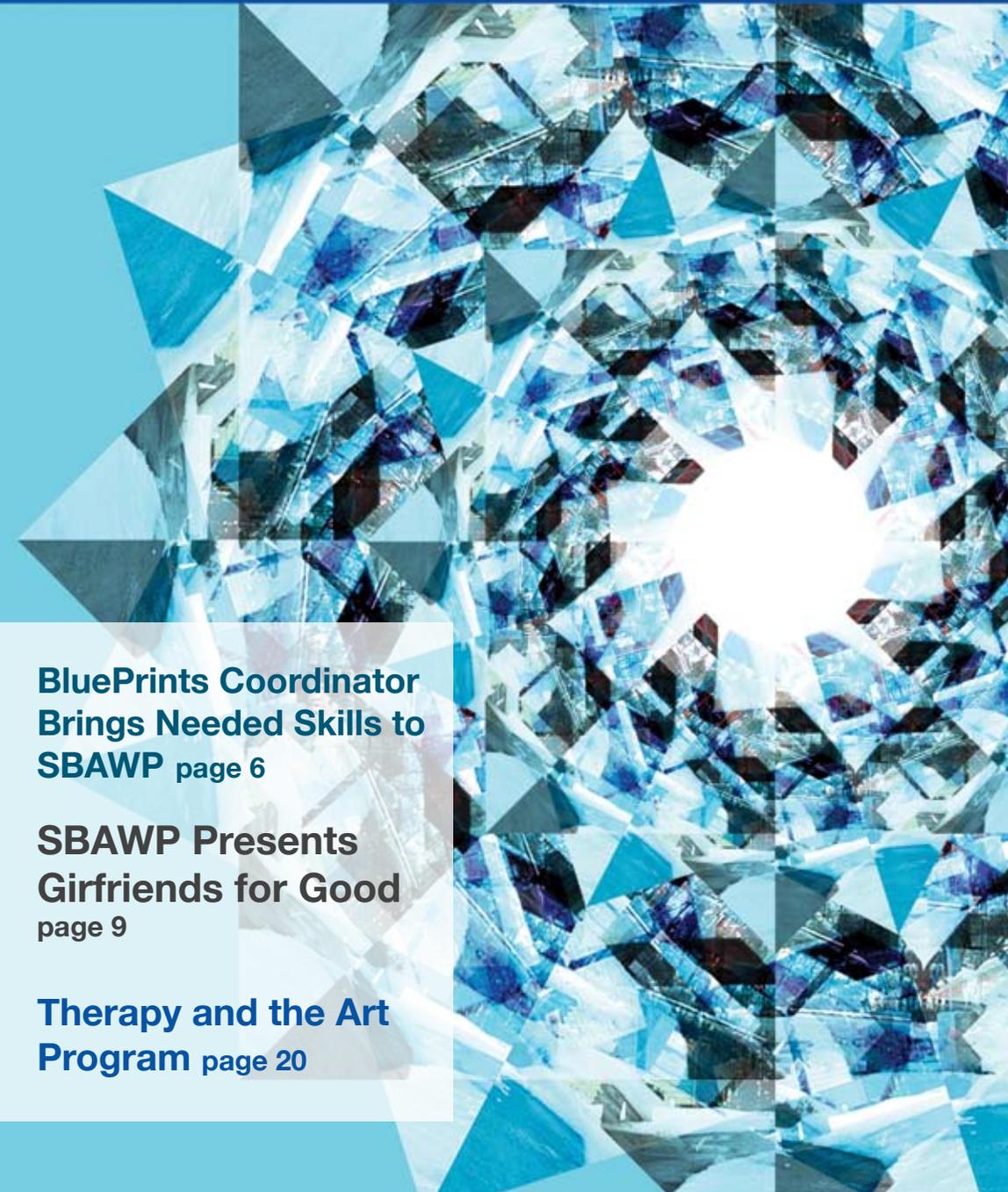


Kaleidoscope

changing . . . adapting . . . growing



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Kaleidoscope

changing... adapting... growing

Winter 2010

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Our Mission

The Spina Bifida Association of Western Pennsylvania is committed to improving the quality of life for people with Spina Bifida and their families by providing a continuum of support services, education and advocacy.



Expectations

My wife and I just became new grandparents!
What an exciting time for us and for the first time
Mom and Dad (my son and his wife)!

As I held this little newborn, I began to wonder what will he be as he grows up but even before that, what will he enjoy doing during his toddler days and then during those early elementary school years. What expectations will be placed on him by his Grandpa or his Dad?

As we start a new year, we all have expectations of what we want to do. SBAWP as an association is no different! Our expectations for 2010 are that we will -

- Expand our programs to be able to touch more lives of those with spina bifida and their families;

- Provide excellent service to those whom we serve;

- Involve more volunteers to give our paid staff the time they need to meet the physical needs of those we serve;

- Stabilize our income by adding fixed streams of income to our mix of foundation and corporate grants; and

- Provide our staff with developmental opportunities.

The pages of the Kaleidoscope and the pages on our website www.sbawp.org will tell the tale as we progress through the year. Our expectations may take some unusual twists and turns along the way. Nonetheless, our goal is to meet and exceed all of our expectations and I along with the rest of our staff pledge to do our best to do just that!

Have a great year! And I hope to see you at one of our special events along the way!

Dick Lynch

{ in your interest

The Year Ahead Camps and Retreats



This past year has been full of changes and excitement, from the renaming of the summer and weekend retreat programs to branching out to new facilities. The FireFly Camps and Retreats program is looking forward to a new year of adventure!



This spring we will continue to spread our wings to reach those who are not living in Allegheny county. This does not mean that we will not continue our retreats in Allegheny county- these retreats will be in addition to the ones we are already doing. It is our hope to have our first retreat outside of Allegheny county in September of this year.

In addition to the planning of the upcoming retreats, we are busy working on putting together our summer schedule, choosing a theme and recruiting staff and volunteers. This year we hope to utilize not only paid staff but volunteers to help ensure that our summer camps continue to deliver the quality care required and expected of our campers! Once we have our dates confirmed for the summer we will begin the application process for both. If you know anyone or are interested in being a volunteer or counselor this summer please call Melissa McCarrell at the office so that we can be sure to get information to you as we have it available.

We are kicking off our 2010 season with a Winter Wonderland Weekend for the Youth and Teens in January. We will be having a Hugs and Kisses weekend for the Adults in February. Beginning in March we will have one retreat for each group per month culminating the spring season with our Mother's Day retreat with a brunch for the Mothers and their families! We hope to see you all there!

The 2010 application packets were sent out last month. If you did not receive one and are interested please call the office and we will get one out to you as soon as possible. You are only required to complete this paperwork once a year and it is required to be updated before you can attend the program. ■



BluePrints Coordinator Brings Needed Skills to SBAWP

In late 2009, SBAWP launched the BluePrints program – a playgroup program designed to help children with spina bifida and other disabilities with motor and social skills while providing their parents with a support group opportunity. In launching the program, SBAWP searched for and found an individual to lead and develop the program.

We thought you would like to know about how the program developed and where it is headed; so in December, Dick Lynch, our Executive Director, sat down with Bonnie Hoolahan, BluePrints Coordinator with a list of questions.



Dick (DL) – Bonnie, you graduated from Slippery Rock University (SRU) but then stayed on and were involved in a program there. Tell us about the purpose of the program and the role you played.

Bonnie (BH) – I was the National Program Coordinator for the “I Can Do It, You Can Do It!” (ICDI) Program at SRU. SRU was awarded this prestigious contract by the National Institute of Health, as a national expansion and evaluation of a mentoring program. SRU was chosen to serve as a national role model and Program Director for launching nine new sites across the United States at schools, universities, and recreational programs. The goal of the ICDI program is to pair healthy individuals as mentors for children and youth with disabilities in order to improve their overall quality of health through activity and healthy eating habits.

As the program coordinator, I worked closely with the nine national site directors in order to ensure that all contract guidelines were followed including monthly reports and newsletters, trainings, and budgeting. In addition I worked directly

with SRU’s I Can Do It, You Can Do It! program site director in the daily running of all programs.

DL – What attracted you to apply to SBAWP for the BluePrints Coordinator position?

BH – After my internship this past summer at the U.S. Department of Health and Human Services, I was very interested in continuing to work in the disability field in the Pittsburgh area, and knew that Spina Bifida did excellent work to improve the lives of their clients. When I saw the posting for the BluePrints Coordinator, I thought it would be a great fit with my past experiences overseeing youth programs at the YMCA as well as my Masters Degree in Adapted Physical Activity.

DL – What makes the BluePrints program unique from other play group programs?

BH – SBAWP created this program to address the unique needs of pre-school children with spina bifida and related disabilities. The group offers children the opportunity to develop social, motor, sensory and cognitive skills by interacting with their peers in a fun and stimulating environment.

BluePrints has been designed utilizing the PA Early Learning Standards for Pre-Kindergarten aged children. These standards are inclusive of all children and act as a framework for quality in Pre-K programs and provide guidance about what children should be able to do when they enter kindergarten.

In addition, it will provide parents a much needed support group. Parents of a child with a disability often spend so much time in hospitals, therapists' offices, and physicians' offices that they may be afraid to let their child play for fear of him/her getting hurt. The parent support group will offer an opportunity not only for children to play together but also for the parents to see that their child is more like other kids than they might think. Parents will also be able to share experiences and watch professionals interact with their child to learn what they can do at home.

DL – Who are our partners in the BluePrints program?

BH – The program is generously funded by the PNC Charitable Trust Grant, Allegheny County Medical Society Foundation Grant, and CVS Caremark Charitable Trust. In addition, we have been extremely fortunate to create great working relationships with the Baierl Family YMCA (Franklin Park) and Sweetwater Center for the Arts (Sewickley) where the classes will be held.

DL – Why did we partner with Sweetwater and Baierl?

BH – We partnered with the YMCA and Sweetwater because they are respected within their communities and we felt that their locations were accessible for families to get to and would be comfortable in terms of space and accessibility. They also offered space within their facilities for the program at no cost to the Association.

DL – Can children with a disability other than Spina Bifida participate in BluePrints?

BH – Absolutely. BluePrints is a playgroup for children with Spina Bifida and any related disability.

DL – What do the parents do while their children are in the playgroup?

BH – The parents will be able to network and communicate as a group about their daily lives of caring for a young child with a disability while providing mutual support for each other. In addition,

we will provide them with vital educational information and an opportunity to talk openly to professionals, as well as their peer support group. This would enable them to obtain as much relevant information and real-life experiences as possible. The parent support group will allow them to see that they are not alone and that there are other families experiencing the similar issues.

DL – What are our current session times by location?

BH – Sweetwater Center for the Arts: Thursday Mornings Jan. 21-April 22, 9-10am (2-3 yr/olds) and 10-11am (4-5 yr/olds)

Baierl Family YMCA: Tuesday Afternoons Jan. 19-April 20, 1-2pm (2/3 yr/olds) and 2-3pm (4-5 yr/olds)

DL – Is there a limit to the number of children in each playgroup?

BH – The playgroup is limited to a maximum of 8 participants in each session.

DL – What happens when you reach the limit of a playgroup and more children wish to attend?

BH – We would add more days and times to accommodate any additional children who wished to participate in the BluePrints program.

DL – What should someone who lives either south or east of the city do if getting to the North Hills area poses some problem?

BH – The executive director of the Baierl Family YMCA, Kenneth Soliday, offered to facilitate meetings with other directors of YMCA across the county so that we could partner with them to expand. Local YMCAs are a great option because they are usually easily locatable in the communities they serve. ■



{ *get involved*



HIGHMARK.
WALK
FOR A HEALTHY COMMUNITY
Organizations Unite to Make a Difference



Save the Date!

Highmark Walk for a Healthy Community Saturday, May 22

The SBAWP has been chosen as one of 59 organizations participating in the Highmark Walk for a Healthy Community on Saturday, May 22 at Schenley Park, Flagstaff Hill! Heading into its 7th year in Pittsburgh, the Highmark Walk for a Healthy Community is a fundraiser that benefits local health and human service agencies in western Pennsylvania.

Highmark Blue Cross Blue Shield underwrites the cost of the walk so that 100 percent of the money raised by walkers goes directly to the 59 participating organizations. The more walkers the SBAWP can recruit the more money we can raise! Last year, one participating organization generated over \$25,000 in funds through its walk participants.

The SBAWP along with Highmark is still in the process of finalizing details for this event. Check back on our website www.sbawp.org in the months ahead for more details on this year's walk and for information on how you can participate. Please mark Saturday, May 22, 2010 on your calendar and start gathering friends, family members, neighbors and co-workers to join you in walking in support of the SBAWP and to ensure a healthier community! For more information on Highmark Walk for a Healthy Community please visit www.walkforahealthycommunity.org.

The SBAWP Presents...

Girlfriends for Good, a new female friendly benefit event in support of children with spina bifida!

On Thursday, February 11th at the D'Vine Wine Bar and Lounge in Wexford, PA, the Girlfriends for Good event will provide attendees with a fun and relaxing opportunity to connect with the association and other like minded women to make a real difference in the lives of children with disabilities. From 5:30 to 8:00 pm, attendees will be pampered with massages and hair and make-up consultations; entertained with live music; and enticed with delicious cuisine, desserts and a wine tasting hour. The benefit will also include a 50/50 raffle, jewelry table, door prizes and much more!

Ladies, we kindly ask that you invite your friends, co-workers, neighbors and family members to attend the benefit with you! Also, please help us

spread the word about Girlfriends for Good. An event flyer is available online at www.sbawp.org for your use to distribute via email or print/mail. History has shown, the more women we can engage, the more powerful the impact! Gentlemen, please consider purchasing tickets to the benefit for the special lady in your life and her best friend as a Valentine's Day gift!

girlfriends for good



A benefit for children with spina bifida and other related disabilities

Thursday
February 11, 2010
5:30 - 8:30

As shown on the event invite on page 23, tickets are \$75 per person; \$55 of which is tax deductible and will be receipted. Please RSVP online by February 5th or call us at 724.934.9600 to RSVP, purchase your tickets and/or to ask any questions. Ticket purchases can be made online or upon arrival to the event. Should you choose to pay upon arrival we ask that you still RSVP.

We look forward to seeing you there and we thank you for all that you do in support of your community and the SBAWP!

Light up
a Life
Campaign



Off to a Great Start!

Just three short months ago, the SBAWP announced the launch of the Light Up a Life Campaign aimed at raising funds online via personalized website pages in support of some of the SBAWP's most crucial programs and services. We are thrilled to announce that we have had nearly 70 individuals sign up as individual campaigners, some of whom formed teams on behalf of particular SBAWP program.

Together, our devoted campaigners have reached out to hundreds of their friends, family members, co-workers and neighbors, raising nearly \$12,000 in just three months! Some of our top campaigners have well surpassed their \$1,000 fundraising goals and have opted to keep campaigning with a new fundraising goal. For example, Ken Ebel, a Fithian House resident, set an initial goal of \$1,000. In just a few short weeks he met his goal and decided to try to raise an additional \$1,000. When asked why he made this decision, he said "At first I was surprised that I reached my goal. My family had a lot to do with getting me there. They have always been super supportive of me and the SBAWP. They were actually the ones who encouraged me to not stop and to raise my goal! It's been a really fun and easy way to give back to the SBAWP."

*You
inspire me. What
a champion!*

Similarly, Libby Powers, also a resident of the Fithian House, has set out to raise \$4,000 in support of the Powers Scholarship fund aimed at providing camperships to those in need. To date, Libby has raised nearly \$1,800 and is determined to reach her goal. Libby shares on her fundraising

page, "As someone who personally attended these retreats and camps for over a decade, I can vouch for how incredibly important they are!"

*Dear
Libby, We are so
happy to contribute...*

The SBAWP is extremely grateful for both Ken and Libby's efforts and to each and every one of our compassionate Light Up a Life campaigners who took the initiative to register to be a part of the campaign and who used this great online tool to ask their loved ones for support! We are also deeply indebted to all the campaign's donors, a majority of whom have never been exposed to the SBAWP! They have generously responded to these heartfelt fundraising requests and continue to do so!

If you haven't already, please take a moment to visit the Light Up a Life Campaign site at <http://lightupalife.sbawp.org>. There you will find instructions on how to become a campaigner, easily set up your own personalized web page and/or how to support one of our existing campaigners. The goal of the campaign is to raise \$250,000 by the end of 2010! Please consider joining the Light Up a Life Campaign because together we can reach this goal and make huge impact on lives of individuals with disabilities. ■

***"As someone
who personally
attended these
retreats and
camps for over
a decade, I can
vouch for how
incredibly impor-
tant they are!"***

***-Libby
Powers***





SBAWP Receives FireFly Grant

Since the Fall Edition of Kaleidoscope the SBAWP has been awarded several grants in support of the FireFly Summer Camps and Weekend Retreats program!

We wish to extend heartfelt thanks to The Edith L. Trees Chairitable Trust, The Margaret M. Patton Foundation, Wal-Mart and Sam's Club for choosing to support the FireFly Summer Camps and Weekend Retreats program despite hard economic times! Also, to the many foundations that wish to remain anonymous, we are incredibly grateful for your continued support of this vital program!

FireFly Summer Camps and Weekend Retreats

All too often individuals with disabilities face social isolation which leads to depression, loneliness, boredom and dependency as a way of life. Dr. Stephen Sheppard, a clinical psychologist associated with the University of Utah Hospital

The program offers participants with a rare and unique opportunity to interact with their peers on a monthly basis.

Rehabilitation Center in Salt Lake City, shares that social isolation is the number one problem he sees in people with spinal cord and other debilitating injuries. "Social isolation contributes to depression, anxiety, and insecurity," he maintains. "It presents a significant barrier to emotional well being for people with physical disabilities."

At the SBAWP, we work tirelessly to avoid this fate for hundreds of children, teens and adults with spina bifida and other related disabilities by providing a number of crucial programs like the Firefly Summer Camps and Year Round Weekend Retreats program. The program offers participants with a rare and unique opportunity to interact with their peers on a monthly basis. Participants also learn to master self-care routines and to develop pre-vocational skills in a fun and stimulating environment. The consistency of peer to peer interaction and the regular reinforcement of life/job skills training builds

a tremendous amount of self-esteem, promotes overall mental wellness and fosters greater independence among those who participate. Simply put, this program is more than just a camp like experience, it is in most cases the only place a growing child or adult with a disability like spina bifida can come to, to feel "normal".

As one of our premier programs, the SBAWP spends nearly \$250,000 annually to maintain the Firefly Summer Camps and Weekend Retreats program, (each Weekend Retreat costs over \$8,000 at 16 retreats per year; Summer Camps cost over \$100,000). This would not be possible without the support of private foundations and corporations in addition to special event proceeds

and our many generous individual donors! While the SBAWP has been blessed to have so many generous contributors over the years, current economic hardship felt by all donors has cut these resources by half. For the first time ever in the 20 years that the Weekend Retreat program has been operational, the SBAWP is faced daily with the decision to cancel nearly half of our Weekend Retreats.

Despite financial limitations, the SBAWP is doing everything in its power to avoid cancellations because we understand how incredibly important this program is to our participants and to their families. We kindly ask that you join us in our efforts to keep this vital programming running! Whether it's through making a direct contribution, attending one of our fundraising events and/ or getting involved with the Light Up a Life Campaign we would sincerely appreciate your support! To learn more about how you can help, please visit us at www.sbawp.org or email development@sbawp.org.

{ OUR BOARD

INSIGHT FROM PETER J. KOCHIS, PRESIDENT
SPINA BIFIDA ASSOCIATION OF WESTERN PENNSYLVANIA

Who are they, where do they come from - do they understand my problems?

Maybe you're reading an article in the Kaleidoscope newsletter, maybe you're looking at a recent email from the association or maybe you drove by the new office and you wonder who is running my Association; do they understand my problems; do they know the history of the Association; am I paying them; how much time do they put into the Association - what in God's green earth do they do?

Well you have a great board of terrific volunteers; no members of the board are compensated. In fact they also serve as one of the largest groups of association donors and they put in many hours, many more than

and when necessary help paint and repair the facilities. Sometimes they take classes on matters germane to our business in order to stay current and able to serve our interest. Many also serve on the Board of SBAWP Housing, the board responsible for oversight of the Fithian House.

Further, there are the other members of the Housing Board themselves, community businessmen, hospital administrators, educators, and ministers as well as more parents of children with spina bifida. And if this were not enough, most have full time jobs and some of those are also the parents of children with spina bifida and deal with all the demands that entails, God bless them.

In this day and age of government regula-

...we put the needs of the kids and young adults we serve at the top of the priority list and to assure it stays a key part of our development...

it takes to just attend four board meetings a year or four to six executive committee meetings or to read all the agreements, reports and plans discussed at those meetings.

You have a very active working board that is intimately involved in the Association's business and challenges. The board members participate in finance, audit, fund raising, housing, medical, human resource, and planning and strategy committees. They also attend and work at Association events, participate in fund raising, counsel employees and others in our population and sometimes just cook pizza for the campers at one of our camps or retreats, as well as assist in various Association's business negotiations

tion, medical developments, technology, legal requirements and economic challenge all overlaid on top of the needs of the community we serve, the demands for a wide variety of skills on our board is vital and the need for those skills is continually on the increase.

First and foremost, this Association was formed as a parental association and we put the needs of the kids and young adults we serve at the top of the priority list and to assure it stays a key part of our development, our by-laws mandate we always have at least one member with spina bifida and at this time, we also have three parents of children with spina bifida on the board, four

of the current thirteen members are personally invested in the decisions of the Association, and trust me they are out spoken and active. If you are the parent of a child with spina bifida or someone who has spina bifida, your interests are well represented on this board. Further, the board is made up of a state representative, two attorneys who help review all legal matters on a pro-bono basis and a pediatric neuro-surgeon who heads our medical committee and helps oversee decisions affecting the well being of our clients.

Board members are also people skilled in marketing, business, and finance. Our treasurer is a CPA who works in the treasury department of Federated Investors and is the parent of a child with spina bifida. We have members with well over 12 years experience with the Association who have helped build this Association and worked hard through many of the trials and tribulations necessary to arrive at this stage of the Association's growth. If any of you were at the recent meeting of parents and clients held at the Family Retreat Center, you know there was lively discussion and some parents were very enthusiastic in their participation. One of those parents, who along with his family have been a long-term supporter of the Association, Mr. Jim Conwell, was outspoken in the interest of the kids. What did the Association do regarding Mr. Conwell's concerns; we invited Jim to join the board and he is now the newest member! And I want to point out that in Jim's acceptance of our offer, Jim did not hesitate, he did not ask for documents, financial information, board minutes. He knew we have challenges. He knows us. He knows what we do. Jim just asked "how I can help?" We're glad to have him with us! Welcome aboard, Jim!

Beyond board members, we are blessed with many advisors to the board who volunteer their time and efforts to assist in guiding our course – people who sometimes say “I

do not have the time to be on a board” and then end up donating at least as much time as if they were on the board. We have two additional doctors who serve as advisors to the Medical Committee, a manager of corporate human resources at a local firm that advises the Human Resource Committee and our Executive Director, and at times lectures the staff on HR and management matters and helps develop and implement the Association's HR policies. Further, we have advisors we turn to as needed in the areas of technology, insurance, real estate and construction, banking and government business.

This is not a board without a vested interest in the people it serves. It is committed to the people it serves because it is made up of the people it serves and

those in service to the kids and young adults that make up our community. They take a leadership role in this Association and that leadership helps us trump the opinions and actions of uninformed influences.

If toward the end of this memo you sense an increase in my own passion, it is because of the tremendous gratitude and respect I have for the people who make up this board, and our staff, who work and fight in the interest of those we serve. We don't manage a facility. We, along with the staff, help kids and young adults who need to use wheelchairs and crutches manage their lives. We make a difference. May God also bless all those who help us help others.

If you wish to show your appreciation for those serving your children and our community please make a donation to our association. ♦

If you are the parent of a child with spina bifida or someone who has spina bifida, your interests are well represented on this board.

{ *in the community*



Thanksgiving and Christmas Dinner in the Community

Thanksgiving and Christmas holidays tend to be a very busy time of year for everyone. It is easy to get caught up in the hustle and bustle of schedules and lists. We sometimes forget to take time to remember the true meaning of the holidays and the importance of spending quality time celebrating the holidays with friends and family. The SBAWP staff and residents decided to take time to celebrate the holidays together this year.

As part of the independent living program at The Gatehouse, the twelve residents met and discussed what foods would be served at a traditional Thanksgiving dinner. With the help of the SBAWP staff, the residents made a list of their favorite foods and then voted on what they would like to prepare as a group and eat for their Thanksgiving dinner on November 17th.

After considerable discussion, the residents opted for the traditional turkey, stuffing, mashed potatoes and of course, pumpkin pie with whipped cream. The SBAWP staff and residents worked together to prepare the food. They even pulled small tables together so they could sit down and enjoy the delicious meal family style. It was an opportunity for the residents to work as a group and spend time together enjoying the finished product. The residents then went home the next week to celebrate Thanksgiving with their families.

Residents at the Fithian House, a fully accessible apartment building where young adults with Spina Bifida live independently, celebrated their first Thanksgiving together on November 19th. The fifteen residents and the SBAWP staff chipped in

to purchase the food items for the dinner. The staff prepared the grocery list and went shopping. The meal was served family style in the large kitchen area. During the course of the meal, attendees went around the table and shared for what they were thankful. The consensus was that the attendees were thankful for friends and family. The residents enjoyed the dinner so much that they decided to start planning for Christmas dinner at the Fithian House. It was decided to include the residents from The Gatehouse and the Villa, a privately owned apartment complex in Allison Park where individuals with Spina Bifida currently live independently.

Over the next few weeks, plans for Christmas dinner at the Fithian House were made. The SBAWP staff and residents decorated a Christmas tree in the lobby. Attendees donated \$5.00 each towards the purchase of the food. Residents Colin McGregor and Crystal Jenkinson donated a turkey. The SBAWP staff went shopping and purchased a ham along with all the other food supplies. As the staff prepared the meal, residents stopped in the kitchen to check on their progress and helped with final preparations. Kenia Hernandez baked cupcakes in her apartment and shared them with the other attendees. The Fithian House kitchen had that wonderful holiday



food smell. The meal was served family style. The attendees enjoyed having their Christmas dinner with friends they don't get to see on a daily basis. The Fithian House residents ended the day by giving the Villa residents a tour of the Fithian House. Villa resident, Eric Nast recently moved here

from New York. He shared that this was his first Christmas in Pennsylvania. Eric said, "It was a really good dinner. I had a good time, but I would like to see more snow!" The attendees are looking forward to more "family" meals together. ■

Hartwood Acres

On December 9th, with our trusty driver Henry at the helm, 11 residents from the Gatehouse and Fithian House headed out on a cold windy night to visit the fabulous light display at Heartwood Acres. The residents were amazed at all the wonderful displays along the 40 minute ride. Along our journey the residents were surprised when a visitor in a red suit boarded the bus to give them a little guided direction about their behaviors for the next couple of weeks. After our visit we headed off to fill our tummies with all the Big Macs, Fish Sandwiches and Fries that we could eat. The bus was full of Christmas cheer and laughter. It was said that they had nice fun and it was delightful! All who went were glad they did!



Caroling

The Gatehouse and Fithian House residents were treated to a special treat on Saturday December 5, 2009. Members from Common Ground Fellowship Church in Clinton, PA visited both houses and sang Christmas carols for the clients. The church members were excited to be there. Lora Myers, who organized the visit from Common Ground, said "We had so much fun! I can't wait to do this again next year!" In addition to singing, the carolers hung around and fellowshiped with the residents. A great time was had by all!



Tax Time!

As the tax season approaches, a lot of us get a little overwhelmed by the process. Did I keep all the important receipts for this or can I claim that as a deduction? It's crazy! While we are not in the business of providing tax advice, you may want to ask your tax advisor about the following items!

Did you know that there are deductions for "Charitable Volunteering"? If you volunteer for a charitable organization you may have deductible expenses. Did you purchase supplies or required equipment? Also, remember that mileage can also be deducted. You should consult IRS Publication 526.

How many of you send your children to summer day camp? Did you know that day camp falls under the Child and Dependant Care Credit? As long as the camp is a day camp and camp officials supervise the child while the parents work you may be able to claim the credit for camp costs. You should consult IRS Publication 503 for all of the specific requirements which determine whether these costs can be deducted.

Happy Tax Season!



Did you know that 112 volunteers gave 1712 hours of their time to improve SBAWP?

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Day on the Set

Hollywood Lights Beckon SBAWP Staff and Clients!

SBAWP staff and Residents at The Gatehouse and Fithian House had the opportunity to appear as extras in the movie "Love and Other Drugs" that was being filmed right here in Pittsburgh this past fall. The film is a romantic comedy that stars Jake Gyllenhaal as a pharmaceutical salesman and Anne Hathaway as a young woman with Parkinson disease. The production team was looking for people with Cerebral Palsy and Spina Bifida to appear in a scene as attendees at a convention for people with disabilities.

"It was exciting being fussed over and photographed."

SBAWP employees Rachel Bestwick, Henry Liu, and Jessica Reese (also a resident at the Fithian House) and Gatehouse resident Ryan Woullard went for a "fitting" at Station Square early in November 2009. They were told to wear and bring two extra "1990 styled outfits". Upon arrival, they were each given a dry erase board with their name and their assigned role in the movie. The production team then took pictures of each person in the different outfits. They even had a selection of 1990 styled outfits for the extras to try on if necessary. The wardrobe team decided which outfit they thought might be appropriate for the day of the shoot. Jessica Reese said, "It was exciting being fussed over and photographed."

On Monday, November 23, 2009, Rachel, Henry, Jessica and Ryan reported to a club in the Southside of Pittsburgh at 7:30 AM for the shooting wearing the 1990 styled outfit that the wardrobe team thought the

costume designer would pick. The costume designer then reviewed the photos that had been taken several weeks before and made the final decision on the appropriate outfit for the shooting.

The SBAWP extras then spent the rest of the day, until 6:00 PM, waiting for their shoot in a small holding room near the producers and staff as the other room with movie extras was overflowing. Caterers provided breakfast and lunch including fish, chicken, pork and salad. The production staff kept checking to make sure that the extras were comfortable

as they patiently waited for their shoot. Finally, the SBAWP extras were called to shoot their scene. They had no speaking parts, but rather were to appear as attendees at the disability convention viewing brochures at sponsor booths. The shoot took about an hour and then the SBAWP extras called it a day.

We at SBAWP have a new appreciation for all the work that goes on behind the scene in order to film one minor scene let alone an entire movie. The extras from SBAWP enjoyed the once in a lifetime experience, but none of them is seeking a career in the movie industry as a result of this opportunity.

Needless to say, everyone is excited about seeing the movie when it is released sometime in 2010. We are all hoping that after all the time and effort put into the convention scene that it does not get cut in final production. Be sure and check it out yourself. Remember, it is called "Love and Other Drugs".

Spina Bifida Clinical Trials: Something to Consider?

Because spina bifida is essentially a birth condition that manifests itself differently for each individual born with this condition, the range of disabilities and associated health problems—physical, emotional, and cognitive – are equally diverse. So, too, are the clinical trials going on for spina bifida.

For example, a recent search of the U.S. National Institutes of Health site ClinicalTrials.gov showed 18 studies for which participants were being recruited, including “Psychosocial Adjustment of Adolescents with Spina Bifida,” “Genetics of Spina Bifida and Anencephaly,” and “Prevention of Post-Operative Bone Loss in Children.” Other clinical trials deal with related issues, such as mobility and exercise, or assistive technologies for people with limb impairment.

The purpose of these clinical trials (essentially research studies) is to test an “intervention” of some sort by following a pre-defined series of steps or processes so that results can be compared, validated, and reproduced by other researchers. In the case of spina bifida clinical trials, the studies generally focus on management of the symptoms, (such as innovative ways to treat urinary tract infections with probiotics), or prevention of the condition (e.g., prenatal repair surgery).

Locating Clinical Trials for Spina Bifida

The best place to check for clinical trials related to spina bifida is, as noted above, the NIH’s site, ClinicalTrials.gov. This authoritative clearinghouse or “registry” of all federally and privately supported clinical trials going on in the U.S. and around the world lists more than 80,000 trials located in 170 countries.

There are two ways to search for spina bifida-related clinical trials on the site. First, you can simply type “spina bifida” in the search box in the upper right-hand corner of every page. This will bring up studies that either are specifically targeted to spina bifida or focus on conditions that may be the result of spina bifida or other conditions (for example, mobility impairments). So this is the “widest coverage” approach.

Second, for more narrowly targeted results, click on “List Studies by Condition” in the

right-hand list on the home page, then “alphabetical listing of conditions” at the top of the “Select a Condition Category” page, then select the “S” condition letter, then Spina Bifida. (Or to shorten those directions, List Studies by Condition > “alphabetical listing of conditions” on Select a Condition Category page) > S > Spina Bifida.) This approach will bring up all studies that specifically target some aspect of Spina Bifida.

Whichever way you choose to search, the results will include, for each trial, the clinical research purpose or goals, who is eligible to participate, locations where the trial is being held, and contact information. There will also be an indication of the trial’s status, e.g., recruiting, terminated, active – not recruiting, completed, not yet recruiting, etc.

Alternatively, if you’ve heard about some new treatment or medication you’d like to search on, you can also see a list of studies by drug intervention, sponsor, and location noted under “Study Topics” on the home page.

Should You Consider Participating in a Spina Bifida Clinical Trial?

The question of whether or not to participate in a clinical trial for yourself – or your child – is an important one to discuss with your doctor or pediatrician. It may have physical as well as emotional ramifications that you need to understand, be prepared for, and know you can live with. On the other hand, by participating, you may improve your own circumstances, or help develop knowledge that will improve the lives of others.

The best way to start thinking about whether a clinical trial might be right for you is to learn more about what clinical trials are, and what to expect, by reading the extensive overview of clinical trials provided in the ClinicalTrials.gov’s “Understanding Clinical Trials” section.

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A Food Ministry with a Servant's Heart

Angel Food Ministries is a non-profit, non-denominational organization dedicated to providing grocery relief and financial support to communities throughout

the United States. The Spina

Bifida Association has been offering Angel Food Ministries to clients and staff since July 2009. Both staff and residents love the quality and quantity of food they receive every month. Anyone can use the service. Here is how it works:

Every month there is a new menu posted at www.angelfoodministries.com. Participants choose the food they would like and payment can be made by check, food stamps or credit card. There are local host sites all over the United States, so just type in your zip code and you will find the closest host site in your

area. The Spina Bifida Association has been utilizing North Park Church as our host site. Every month North Park Church works with the staff here at SBAWP to gather all the orders and then the following week, usually a Saturday, the staff picks up the orders and delivers them to all the residents at the Villa Riviera and Fithian House locations.

This service offers new food choices to residents while assisting with portion control and a balanced diet. Angel Food Ministries is also great because it helps our residents save money on their groceries and transportation costs that they would normally pay for ACCESS to take them to the grocery store. Thanks for all your help North Park Church and Angel Food Ministries! For more information please go to www.angelfoodministries.com. or call 724-934-9600.



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{ *from study to practice*

Therapy and the Art Program

According to the American Art Therapy Association “Art therapy uses the creative process of art making to improve and enhance the physical, mental and emotional well-being. It is based on the belief that the creative process involved in artistic self-expression helps individuals of all ages resolve conflicts and problems, develop interpersonal skills, manage behavior, reduce stress, increase self-esteem and self-awareness, and achieve insight.”

Last Spring, SBAWP staff member John Merolillo decided to introduce Art Therapy to Fithian House residents. Drawing on his experience as a certified Art teacher, John wanted to provide residents with a creative outlet to relieve stress and fight boredom. What began as a modest project nearly a year ago has transformed into a budding and well received Art Therapy program. John shares with us both his and the resident’s art therapy experience over the past eight months:

We started with the basic elements of design

such as color, value, form, line, space, and texture. Realizing that many of these elements were very foreign to the residents I had to reshape the program focusing more on the actual techniques. I knew that if they had a strong grasp on these techniques they could focus more on the creative and therapeutic aspect of art and self expression.

Many of the residents were overwhelmed with the elements of design. We took a full 2 months to hone and develop skills and learn about each element. Participants started out not being able to draw a straight line or a circle. After a lot of time and practice each resident became a student of art. They all gained the necessary skills to further develop their own style and form of expression. For example, resident Jack Vasvary proved to be very detailed and aimed for perfection in all of his designs. John Moroney expressed a very rough and jagged style while he de-



Fithian House resident Justin Savage and SBAWP staff John Merolillo

veloped his drawings. Opposite of John is Justin Savage who had a very soft and expressionistic style.

After all the residents became professionals at shading we started a charcoal drawing on landscapes using various pencil and charcoal techniques. We used the artist Ansel Adams for reference. This lesson got many of the residents excited about the art class because all of the skills they were learning finally came together. It took us about a month to complete and they were all very satisfied with the results. I myself was thrilled with their progress and their enthusiasm!



Fithian House resident Jack Vasvary

Our second large scale project focused on self portraits using charcoal. This was the most difficult lesson by far. We spent a few weeks learning different ways to draw facial features such as noses, eyes and ears. Kenia Hernandez was one student that practiced especially hard and on her own time. This project was so in depth that I had to set up special one on one times for them to come see me and work on their portraits. We spent many hours on each drawing as well as talking about what they saw in themselves. The project was meant to give the residents more self confidence,

which I believe it did. After they saw the end results they were very proud of what



Justin Savage, self portrait

they had accomplished. As their teacher, I was extremely proud of them too!

The last few months of class were challenging to coordinate. Many of the full time students were in and out of the hospital. It was extremely hard to keep everyone on track. I had to come up with a project that everyone could do without having to teach them a lot of skills. We started abstract sculptures designed to look like miniature stone sculptures. These were constructed out of wood blocks, that the residents cut themselves, and coat hangers and pantyhose. They all came out amazing. This project taught them how to use form and space to create a balanced abstract sculpture.

Classes are set to resume at the end of January. I am trying to collect supplies such as brushes and water color paper. We will be starting on watercolors. The artist we will be focusing on is Claude Monet.

If you would like to support the budding Art Therapy Program please visit the Light Up a Life website at <http://lightupalife.sbawp.org/> select Contribute to a Campaigner, Donate to an Individual and then select John Merolillo from the list. John has set a goal of \$3,000 for the program. To date he has raised \$1,555! If you would like to contribute art supplies please contact John at the Fithian House 724.934.9688. ■

Calendar of Events

February, 2010

- 2 | **STRIVE** Session 4 – Application Deadline
- 2, 9, 16 & 23 | **BluePrints** Program at Baierl Family YMCA
- 4, 11, 18 & 25 | **BluePrints** Program at Sweetwater Center for the Arts
- 5 | **STRIVE** Session 3 – End Date
- 11 | *girlfriends for good* at D’Vine Wine Bar & Lounge
- 12-14 | **FireFly** Adult Retreat/Woodlands
- 15 | **STRIVE** Session 4 – Start Date

March, 2010

- 2, 9, 16, 23 & 30 | **BluePrints** Program at Baierl Family YMCA
- 4, 11, 18 & 25 | **Blue Prints** Program at Sweetwater Center for the Arts
- 5-7 | **FireFly** Adult Retreat
- 12-14 | **FireFly** Youth Retreat

April, 2010

- 1, 8, 15, 22 & 29 | **Blue Prints** Program at Sweetwater Center for the Arts
- 5 | **STRIVE** Session 5 – Application Deadline
- 6, 13, 20, & 27 | **BluePrints** Program at Baierl Family YMCA
- 9 | **STRIVE** Session 4 – End Date
- 16-18 | **FireFly** Youth Retreat
- 19 | **STRIVE** Session 5 – Start Date
- 23-25 | **FireFly** Adult Retreat

May, 2010

- 4, 11, 18 & 25 | **BluePrints** Program at Baierl Family YMCA
- 6, 13, 20, & 27 | **BluePrints** Program at Sweetwater Center for the Arts
- 7-9 | **FireFly** Youth Retreat
- 22 | **Highmark Walk** for a Healthy Community



The Spina Bifida Association of Western PA Presents

girlfriends for good



Thursday, February 11, 2010
5:30PM-8:00PM
D'Vine Wine Bar & Lounge
12017 Perry Highway
Wexford, PA 15090

d'vine
wine bar & lounge

Live Jazz Music • Massages • Hair and Make-Up Consultations
Manicures • Jewelry Table • Wine Tasting from 6:00–7:00pm
Delightful Cuisine • Delectable Desserts
Cash Bar featuring the \$5 “Bifini” • Door Prizes and much more!

Please RSVP online by February 5th at www.sbawp.org or call us at 724.934.9600
Tickets are \$75 per person; \$55 of which is tax deductible • Ticket purchases can
be made online at www.sbawp.org or upon arrival to the event.

Girlfriends for Good is a benefit for children with spina bifida
and other related disabilities

BluePrints

For Children 2-5 Years Old with Spina Bifida and Related Disabilities

- Develop Social, Motor, Sensory & Cognitive Skills
- Interact with Peers in Playgroup Environment
- Structured and Unstructured Play
- 14 Week Program
- Professional Supervision
- Networking for Parents
- Parents participate in conclusion of activities

Tuesdays

Baierl Family YMCA

Thursdays

Sweetwater Center for the Arts

For more information:

visit: www.sbawp.org

email: ProgramInfo@sbawp.org

call: 724-934-9600



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Save the Date

Walk in support of the SBAWP
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Saturday May 22, 2010
Schenley Park, Flagstaff Hill



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